McEwan C and Butler R (2007) 'Disability and development' *Geography Compass* 1/3, 448-66

Disability and development: different models, different places

Introduction

> While people in the rich world are talking about Independent Living and improved services, we are talking about survival (Joshua Malinga, leading Zimbabwean disabled activist, in Stone 1999, 1)

Debates about disability within geography, as well as in disability studies more generally, have been largely urban, Anglophone and western-centric. Not only have industrialised societies remained the predominant focus of attention (Power 2001), but the debates themselves are rooted within an often unacknowledged western context. In addition, it is only relatively recently that the issue of disability has emerged within the development literature. This is perhaps surprising given the impact that human development approaches – which place emphasis on human beings as ends rather than means and on broader notions of social well-being and justice than development as material prosperity – have had on studies of development. Indeed, some commentators suggest that while there ought to be clear links between human development and disability issues, the latter have been relatively neglected in comparison with issues such as gender justice and sustainability (Harriss-Whyte 1996; Baylies 2002). Attitudes towards disability in developing countries have undoubtedly played a part in this lack of visibility, since there

is still the notion in some places (Latin American countries are prime examples) that issues regarding disability are a private or at least a family matter (Gatjens 2004).[1]

The relative neglect of disability within studies of development is even more surprising given its prevalence in developing countries and its mutually constitutive relationship with poverty. According to the United Nations, three quarters the world's disabled people live in developing countries (Helander 1992). Impairment and, in turn, disability are both causes and consequence of poverty; disabled people in developing countries are often among the poorest of the poor and measures to tackle poverty are unlikely to be successful unless the rights and needs of disabled people are taken into account (DfID 2000). While it might be assumed that achieving international development targets for social, economic and human development will reduce prevalence in many poor countries, it is only recently that development agencies and government departments (e.g. the UK's Department for International Development) have recognised that specific steps are required to prevent disability, and to ensure that disabled people are able to participate fully in the development process and claim their rights as full and equal members of society.

In the light of this, the aims of this paper are two-fold. Firstly, the paper aims to bring together debates about disability and development and to trace some of the most salient issues concerning disability in developing countries. Secondly, it aims to further debates about the significance of geography in disability studies, to highlight some of the problems with the western-centric focus of disability models and to extend understanding of the shifting and complex landscapes of disability in developing countries. The paper

[1] Indeed research in Britain has shown that such attitudes amongst members of some minority ethnic groups mean that they do not take up services aimed at disabled people to the same extent as white British people (Priestley 1995).

begins by recapitulating some of the difficulties involved in defining disability, especially cross-culturally, and examines some of the major criticisms within development literatures about western-centric definitions. It then examines various approaches to disability in the context of developing countries, drawing on literatures that have explored and critiqued issues of prevention, social models of disability, the significance of government policy and rights-based approaches in developing countries and debates about community rehabilitation. The paper points to a series of challenges that remain in, and lessons that might be learnt from, developing countries and concludes by reiterating the significance of geography to the creation of more appropriate policies and practice with regard to disability issues in developing countries.

The problem of defining disability

It is axiomatic that defining disability is fraught with problems, which are compounded in cross-cultural analyses of disability issues. As Whyte and Ingstad (1995, 5) argue, "any attempt to universalize the category 'disabled' runs into conceptual problems of the most fundamental sort". Not only does the category refer to a broad range of physical, mental and sensory impairments, some more manifest than others, but disability is also a socio-cultural construction. Clearly, disability does not mean the same thing across cultures and over time. For example, it has been widely acknowledged that the place of disabled people in industrialised societies has changed as social, cultural, economic and political environments have developed (Oliver 1990, Barnes 1991, Gleeson 1999). However, definitions of disability are required to shape policy and there is a general tension between the need, on the one hand, for internationally shared meanings that enable cross-

cultural information exchange and, on the other hand, the need to recognise cultural differences (Stone 1999, 2). In the recent context of development, disability has been defined as "Long-term impairment leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community" (DfID 2000, 2). This definition counters the reduction of disability to medically-defined impairment by recognising the social dimensions of disability, a topic to which we return to subsequently.

As Power (2001) argues, what partly defines disability in developing countries is the 'voicelessness' and institutional neglect of disabled people who are often forced to take positions on the peripheries of their societies. This is both a product of prevailing attitudes within these societies but can also be attributed to ways in which disability was institutionalised under colonialism. In many pre-colonial societies, disabled people were pragmatically accommodated by what they were able to contribute to the life and welfare of communities. In pre-colonial southern Africa, for example, disabled children participated to varying degrees in community life by carrying water, herding cattle or assisting with domestic chores (Kisanji, 1995). Family and kinship ties, competence in doing tasks considered useful for the household and the ability to behave in a socially acceptable manner determined the status and inclusion of a person within a community (Ingstad, 1999; Kabzems and Chimedza, 2002). Obviously, the degree and type of impairment determined levels of inclusion and this is not to say that marginalisation and persecution did not take place, but the treatment of disabled people was often very different in pre-colonial and colonial contexts.

Under colonialism, humanitarian models were imposed, with disabled children attending special schools run by a church or charitable NGOs. The charitable link provided communities with personnel, funding and equipment that served as an alternative source of attitudes towards disabled people. Churches and charities very often filled, and continue to fill, gaps in provision for disabled people. However, they also imported attitudes that emphasised medical/charitable models of disability, development and service delivery; aid was usually contingent upon the adoption of the philosophy of the donor or service provider and this is still very often the case (Kabzems and Chimedza, 2002). As with 'development' more broadly, historically the power to define disability has resided with professionals – mostly western, mostly medical, educational or administrative. Recent decades have seen new and challenging definitions coming from disabled people themselves but, as discussed subsequently, from mostly western, white and educated disabled people (Stone 1999). However, greater recognition is currently being given to the socio-cultural dimensions of disability as a means of mitigating some of the more problematic and often western-centric approaches. Raising the complex issues of socio-cultural dimensions of disability is not new (see Goffman 1963, for example). However, the fact that disability is socio-culturally constructed and also constitutive of social, economic, political and psychological relations between both individuals and/or institutions has considerable significance for conceptualising disability and development in a range of different contexts. In what follows, we explore critically a number of different approaches to disability as they relate to development more broadly, focusing on what we perceive to be the central issues for rethinking disability and development policy and practice.

Prevention of impairment and disability

The most frequently made connection between disability and development in developing countries is the link between poverty and impairment (Stone 1999). The root causes of impairment in poor countries are malnutrition, poverty, landmines and lack of services and these hit the poorest hardest (Chambers 1983). A considerable proportion of impairments in developing countries are a direct result of poverty, injustice and geopolitical interventions in which industrialised countries are often deeply implicated.

One example of the link between poverty and disability is childhood impairment. As Bartlett (2002) argues, extraordinary numbers of children around the world are impaired every year as a result of preventable injuries that occur within homes and neighbourhoods; the percentage of injuries per capita is much higher in the poorest countries. Impairments are often a consequence of injuries caused by open fires and exposed kerosene heaters, unprotected stairways and heights, poor quality construction, lack of safe storage of chemicals and poisons, piles of debris and poor waste disposal, heavy traffic and a scarcity of safe play areas for children. The lack of access to affordable emergency health services increases the number of long-term impairments. It is generally acknowledged that the problem of injury-related impairment is growing in absolute terms in poorer countries (see Forjuoh and Gyebi-Ofusu 1993; Sharma *et al.* 1993; Zwi *et al* 1996; Meyer 1998; Deen *et al.* 1999; Guastello 1999; Krug *et al*. 2000; Bartlett 2002). Evidence suggests that children living in poverty are disproportionately affected by injuries (Berger and Mohan 1996; Butchart *et al.* 2000; Laflamme and Diderichsen 2000). Not only are physical environments more hazardous but families are

also vulnerable to psychosocial stress that accompanies childhood injury; financial problems, poor health and challenging living conditions also result in lower levels of supervision of children. While figures are often unavailable, anecdotal evidence suggests that accidents are especially common amongst working children in developing countries. An ILO survey of the Philippines, for example, found that more than 60% of working children were exposed to hazards at work and, of these, 40% had suffered serious injury (ILO 1996 in Bartlett 2002, 3).

It would seem, therefore, that a large amount of disability is preventable, often through relatively simple and low-cost interventions. Measures to improve general living conditions and standards can have a positive effect in reducing the incidence of disability; improvements in health services reduce risks and mitigate the effects of impairment when it occurs. Efforts to eradicate specific diseases can also have widespread and significant effects. The commitment by the World Health Organisation to eradicate polio, for example, has had a significant impact in reducing the number of cases around the world from 350,000 in 1988 to only 5,000 in 1999 (DfID 2000). Similar health programmes have been rolled out by international development agencies (e.g. the UN) to combat other diseases such as leprosy, river blindness and HIV-AIDS, all of which can have severe disabling effects, but it is important that these programmes do not separate issues of disease eradication from underlying causes relating to poverty. Access to improved health care systems that better serve the needs of the poor is critical, which includes enabling even the most marginalised of people to access sexual and reproductive health services. That disabled people often face the greatest difficulties in accessing health care needs to be considered when measures are taken to improve provision.

Of course, impoverished people still have the greatest difficulties in accessing clean water supplies and sanitation; they encounter greater risks of exposure to environmental hazards and have poorer nutrition, all of which contribute to the incidence of impairment and long-term disability. They are often the most vulnerable to the worst effects of conflict and reliant on the least safe forms of transport. Any attempt to prevent disability in developing countries, therefore, must deal with underlying poverty and its associated risks.

Social models of disability

In addition to a greater focus on development policies aimed at prevention of disability, recent years have witnessed a shift from medical models of disability to ones that acknowledge the social dimensions of disability (see, for example, Butler and Bowlby 1997; Tregaskis 2002). For example, the International Labour Office formerly drew a distinction between three concepts of disability (physical, occupational and general) (ILO 1989, 74). This was a medical/occupational method of assessing disability and the effect on earning capacity and was criticised because its point of departure was a non-disabled, employed person who became disabled through accident, injury or disease; it made no provision for a person born disabled or becoming disabled before having an opportunity to enter the labour market. Equally, this model of disability centralised western medical knowledge and thus reflected the "postcolonial paternalism" (Lee 1997) of many international debates about disability. More recently, the ILO Code of Practice on Managing Disability in the Workplace, adopted in 2001 by experts from developing and industrialized countries, recognizes the "need for definitions to reflect the social

dimensions of disability, be in harmony with human rights principles" and allows for "variation in national interpretations of disability" (http://www.ilo.org/public/english/employment/skills/disability/download/adhoc.doc).

These shifts in international definitions reflect the success of disability activism, primarily in industrialised countries. Social models of disability, which see the problem not as located in the individual, but in a society, economy, political system and culture that fails to meet the needs of disabled people, was developed primarily by British disabled people and activist allies. Disability, in this sense, is social disadvantage and discrimination and in order to make a change in disabled people's lives there is a need to change society and the way society treats people who have impairments. Whilst the term 'the social model' has become "a gloss for a range of theoretical and methodological commitments"(Dewsbury *et al* 2004: 145), these commitments are rooted in specific notions of civil rights, the need for inclusion and the removal of disabling barriers to full participation. It is significant that the recent ILO statement acknowledges that while social models are appropriate for politicised disabled people in industrialised countries, they might be inappropriate elsewhere. As critics have argued, imposing western-centric social models of disability in developing countries without consideration of local historical and cultural practice would be more like imperialism than empowerment (Miles 1992; Stone 1997).

Most, if not all social models are based on the assumption of the availability of technical and environmental solutions, in addition to cultural shifts, which have resource implications. Even in relatively wealthy industrialised countries where such models have been developed and embraced, disabled people do not have full entitlement because of

costs to individuals, institutions and arenas of government (Oliver 1990). Caution is thus required when exploring the wider relevance of disability debates grounded in particular cultural values and geographical spaces. For example, Komardjaja (2001a; 2001b) argues (primarily in the context of Indonesia) that western-centric debates about accessibility and barrier-free environments are less relevant than the need to enhance the general quality of life for disabled people, including reducing illiteracy, increasing access to information, and participation in economic and political decision-making. Clearly, issues for disabled people in developing countries are profoundly different to those in industrialised societies. In developing countries, it is rare to see ambulant disabled people using mobility aids such as leg braces, crutches, walking canes and wheelchairs. As Komardjaja (2001b) argues, for impoverished disabled people the streets are the places most suitable for begging. Generally, disabled people in such contexts are not pedestrians; rather, they are on the streets for specific purposes, often related to survivalist strategies. Sidewalks along main roads and thoroughfares are strategic sites for economic activities of low-income and informal traders who hardly leave space for pedestrians (Ballard and Popke, 2003). Therefore, concerns with access are not always appropriate in such contexts, where disabled people are preoccupied with coping and surviving. These debates bring international classifications and universalising models of disability under scrutiny, particularly if they inform policies that might be ignorant of geographical and cultural differences.

There are questions, therefore, about whether current social models that have been formulated in industrialised countries are appropriate in developing countries, where resource constraints are extreme and where issues of prioritising are urgent. Social,

economic and political structures may be common concerns, but the forms, causes and the resulting salient issues for disabled people differ. The issue of poverty is again significant. There are greater disabling barriers that prevent disabled people in poorer countries from acquiring education, employment and access to appropriate support and services. Some barriers are rooted in local attitudes to disability; others are rooted in broader structural processes of poverty and injustice, but it has only recently been recognized that "local and global factors impact on perceptions of and responses to impairment and disability" (Stone 1999, 6).

Reflecting some of these concerns, a number of authors (for example, Butler and Bowlby 1997, Hughes and Patterson 1997, Imrie 2004) have argued that both medical and social models, while capturing aspects of disabled people's lives, are problematical for failing to recognise that biology and society (including its culture, economy and politics) are entwined in a dialectical relationship. This implies that:

> physical and mental impairment, in contributing to functional limitations of bodies, cannot be discounted as ephemeral in the construction of disability and disabled people's lives. Rather, a focus on interactions between functionally impaired bodies and socio-cultural relations and processes is seen, by some, as crucial in the development of a non-reductive and non-essentialised understanding of disability (Imrie 2004: 288).

As Imrie argues, these ideas are gaining ascendancy in a range of important developmental contexts, most notably in the World Health Organisation's (WHO 2001) *International Classification of Functioning, Disability and Health*. This seeks to develop the conception that "mind, body, and environment are not easily separable but rather

mutually constitute each other in complex ways" (Marks 1999, 25) and conceives of disability as "a compound phenomenon to which individual and social elements are both integral" (Bickenbach *et al.* 1999, 1177). This is clearly an important development in international understandings of disability. However, as Imrie suggests, there is still a lack of clarification on the definition of impairment and the principle of universalisation as the basis for disability health and social programmes remains questionable. The shifting and complex terrain of disability in developing countries brings these issues into sharp focus.

Rights-based approaches

One positive aspect of social models of disability is that they provide an opportunity for cross-cultural differences in the interpretation of disability to be accommodated in our understanding. This has helped raise the significance of how societies interpret and react to disability and the importance of tackling discrimination towards disabled people. Considerable gains have been made by activists in some developing countries in the field of civil rights, which in turn also places emphasis on the significance of government policy within developing countries. Two well-documented examples are South Africa and Uganda.

Disability issues came to prominence in South Africa during the political transformation in the early 1990s, when minority groups were quick to organise and seize the opportunity to shape new state institutions and the nature of democracy being constructed. Disability activists were among these minority groups lobbying hard for recognition and guarantees of rights and equality within the new dispensation. As a consequence of high visibility and activism, the Office of the Status of Disabled Persons

was established in the Office of the President and is thus located at the heart of government. The National Co-ordinating Committee on Disability (NCCD) played a key role in the establishment of the Disability Program and the drafting of the 1997 White Paper on Integrated National Disability Strategy, which aims to create an enabling environment that will lead to the full participation and equalisation of opportunities for persons with disabilities. The OSDP has also developed mechanisms and capacities to facilitate the integration of disability issues into government development strategies, planning and programmes, as well as the coordination, monitoring and evaluations of these at national, provincial and local government levels. One of its main activities has been to train previously marginalised disability groups in effective advocacy skills.

Protection against the contingency of disability is provided through the Constitution, primarily via the anti-discrimination clause, which protects *all* people against direct and indirect discrimination. Disability is mentioned as one of the arbitrary grounds, undoubtedly a product of disability activism, which presented itself as a movement for full citizenship rights. Despite this, disabled people in South Africa face high levels of inequality and discrimination and labour and social security laws continue to define disability with reference to a particular medical model (Truter 2001). For example, Section 1 of the Employment Equity Act (1998) defines disabled people as "people who have long-term or recurring physical and mental impairments which substantially limit their entry into or advancement in employment". Despite this, the legislation has been significant in allowing disabled people to claim their rights as citizens.

The 1998 Employment Equity Act is important in prohibiting unfair discrimination against disabled people and providing for affirmative action measures. These include modifying or adjusting jobs and working environments to accommodate disabled people and numerical goals to address under-representation in the workplace. The public sector was required to achieve a 2% level of employment of disabled persons by 2005, while bigger employers have to register employment equity and skills development plans setting numerical targets in terms of race, gender and disability (Rowland 2002). The 1999 Skills Development Levies Act aims to improve the employability of those who find it difficult to enter the labour market, particularly people from previously disadvantaged groups, including disabled people. However, the Department of Labour has set equity targets for skills development initiatives at only 4% of disabled people (Cape Business News 2001), which does not equate with lowest estimates of disability within South Africa.

The South African government has attempted to reform other laws to counter persistent inequalities. Both the White Paper for Social Welfare (1997) and the White Paper on an Integrated National Disability Strategy (1997) acknowledge that South Africa's security system has in the past not operated in the interest of disabled people. The former foresees the formulation of a policy on social security for disabled people and the government has endorsed the World Programme of Action concerning Disabled Persons, the UN Standard Rules and the UN Charter on Rights for People with Mental Handicaps (White Paper 1997, 22). This represents a major change in government thinking on disability issues in accordance with international developments. A wide range of issues, such as public transport, employment, accessible communication, integrated

education and the restructuring of social security benefits are addressed. It acknowledges that social security legislation tends to be discriminatory towards disabled people and sets as the objective a social security system that meets their needs. This includes an appropriate assessment method, accessible information and payout facilities, proper administration, effective feedback mechanisms and a co-ordinated social security safety net (White Paper, Ch 2). In addition, a National Environmental Accessibility Programme is underway, focusing on rural areas, education and employment (Power 2001).

The case of Uganda is also notable in that disabled people have achieved a higher level of political representation than in any other country (Ashton 1999, cited in DfID 2000). Like South Africa, Uganda has a relatively new constitution that provides for the representation of the disability movement at all levels of political administration. At parliamentary level, five seats are reserved for disabled people, one for each of the four regions of Uganda and one representing the interests of women with disabilities. Moreover, in local elections, at all levels of government, there has to be at least one representative with a disability. This prominence within government is seen as essential to ensuring that the needs of disabled people are fully articulated within government policy.

Whilst the rights-based social model adopted on paper in some developing countries appears to be progressive, there are still significant questions over the possibilities of delivering what is promised. These questions to some extent revolve around the limitations of social models discussed previously, particularly in terms of poverty, access to resources and a profound rural-urban divide in many developing countries. Even in relatively resource-rich countries like South Africa, it is difficult to see

how disabled people living in impoverished rural communities, where there are significant technology and service provision gaps, will be able to claim their rights under recent legislation or to improve the circumstances in which they live. Many Latin American and Caribbean countries have only recently approved disability legislation, but there is still very little effective compliance (Gatjens 2004).

The macro-economic context in which developing countries have to operate also raises doubts about the possibilities of translating progressive legislation into reality for disabled people. South Africa, for example, has undergone what various critics have described as a self-imposed structural adjustment (Bond 2000; Marais 1998; Hart 2005), with the effect that the progressive welfarist and redistributive policies have been superseded by a neo-liberal macro-economic policy. This raises questions about the effects of a restricted social welfare budget on populations dependent on social welfare, especially those with disabilities. In many developing countries where progressive legislation has been adopted the biggest obstacle to change appears to be the private sector, which has been slow to include, promote and address the legacy of discrimination against disabled people.

The key issue for developing countries is whether, in a neo-liberal macro-economic context, the guarantees to equality within constitutional and progressive legislation can be translated into *de facto* improvements in the lives of disabled people. If social models are seen as the solution, which imply a level of state spending on improving technology and access to resources, there are questions about whether this will be possible given enormous budgetary constraints. In sub-Saharan African countries, in particular, the effects of HIV/AIDS and economic globalisation have the potential for

negative impacts on the welfare of disabled people. Kabzems and Chimedza (2002) point out that in South Africa, for example, there is already less talk of world class facilities for disabled people and more talk of the "common good" – trying to prevent disabilities through providing access to clean drinking water, immunisation programmes and injury prevention.

Social models also recognise that further constraints are created by existing cultural barriers, which are not likely to be overcome by legislation and policy alone. Social acceptance and attitudes are both reflected and constantly reinforced by the vocabulary employed to refer to individuals with disabilities. Many southern African languages, for example, use prefixes designated for noun classes referring to objects of animals when referring to individuals with disabilities (Devlieger, 1998) – spoken and written language reinforces their marginalisation within society. In many sub-Saharan African countries negative cultural attitudes persist, where disability in children continues to be associated with maternal wrongdoing, witchcraft, evil spirits, or divine punishment (Kabzems and Chimedza, 2002). A family might be accused of "sacrificing" the child in exchange for good crops or a father will accuse his wife of promiscuity in order to deny his part in the "creation" of disabled child (*ibid.* 151). And in many developing countries around the world, international aid agencies have perpetuated the public perception that disabled people are a burden in need of support from charitable organisations and external agencies; it is not surprising, therefore, that negative attitudes exist within communities where resources are scarce. Thus, although the civil rights of disabled people in some developing countries are increasingly protected, cultural barriers still remain and are continually reinforced. One remaining positive factor, however, is that in

387 countries where progressive policies have been adopted civil society structures have also
388 been put in place and can play a major role in lobbying and advocacy. Awareness
389 campaigns, which receive some state support, have some potential in empowering
390 disabled people (Gleeson 1999) and advocacy is important in changing attitudes (Parker
391 2001).
392
393 **Community-based rehabilitation**
394 In some ways related to debates about cultural barriers, community-based rehabilitation is
395 an approach that has grown out of the debate between social and medical models of
396 disability. It attempts to combine physical rehabilitation through medical intervention and
397 care with empowerment and social inclusion through the participation of disabled people,
398 as well as their communities, in the process of rehabilitation. This has often been claimed,
399 particularly by aid agencies and development organisations, to be the most effective way
400 of making use of scarce resources and of socially integrating disabled people. Emphasis
401 is placed on participation, active community support, specialist medical inputs and
402 indigenous knowledge and practices. Advocates believe it empowers individuals to take
403 action to improve their own lives, but critics are numerous.
404 Perhaps most obviously, concerns have been raised that negative institutional
405 practices and attitudes have, in many cases, simply been relocated into communities
406 (DfID 2000). In addition, aid agencies advocating these approaches are often unaware of
407 earlier, imperialist attempts to rehabilitate disabled people. As Miles (2001) argues, they
408 often accept the conventional mythology that "nothing was done for disabled people"
409 before a phase of "institution-building" in the 1960s, which they now wish to replace

410 with “community-based” rehabilitation and “inclusion”. They thus ignore the fact that
411 community-based rehabilitation, very much the fashion since the 1980s, is simply an
412 updated, less obviously imperialistic version of missionary responses in the 1890s (Stone
413 1999). They might be well-meaning, but they are often insensitive and inappropriate to
414 local practices and perceptions. Most importantly, these schemes often under-estimate the
415 support of families and communities already in existence for disabled people (Rao,
416 2001). Disability service developments are often dominated by the disparate trends of
417 European countries funding them. For example, Scandinavian countries have been active
418 internationally in promoting disability issues in southern Africa starting with
419 normalisation, integration and community-based services and inclusion. Policy affirms
420 the need to include persons with disabilities at all levels and stages of projects. Yet, as
421 Kabzems and Chimedza (2002, 149) point out: “It remains rare for a person with a
422 disability to be on the project payroll, whether in the capacity of consultant, accountant or
423 tea lady”.

424 This lack of user involvement in planning in disability and development appears
425 to be widespread despite stated policies to the contrary. A study by Flower and Wirz
426 (2000) explores how selected European-based international non-governmental
427 organizations (INGOs) facilitate the participation of disabled people in their planning
428 process. While INGOs involve disabled people’s organizations (DPOs) in their planning
429 of services and projects this is most commonly through sharing information rather than
430 through consulting with them, including them in decision-making or supporting action
431 initiated by them. The study found that if there is no assurance that ideas raised will be
432 implemented, then there is no guarantee of the participation of DPOs in the planning

process of INGOs. Yet despite failing in facilitating participation, INGOs have helped to strengthen DPOs, encouraging their formation and making disability an issue that cuts across sectoral boundaries. This might facilitate the participation of disabled people in the planning process of INGOs in the future, but there is still a long way to go.

Many critics argue that models of community-based rehabilitation and inclusion, imported from countries with much stronger economies and longer histories of universal primary education, child-centred education, and educational research, have seldom been culturally or conceptually appropriate to the countries in which they have taken place (see Miles 1996; Lorenzo 2003; Metts and Metts 2003; Millward *et al.* 2005). Rao (2001) argues that the status of disabled people in the majority world is complex and there is great variability in the ways in which they are treated. Thus:

> it is worthwhile to understand the indigenous ways in which disabled people have been accommodated. Recognising the differences in social, cultural and historical contexts may be critical in implementing inclusion initiatives, which are culturally appropriate (*ibid*., 533).

It remains the case, however, that external ideologies are often imposed that do not necessarily match local practices and attitudes towards disabled people. As Kabzems and Chimedza (2002, 150) point out, "the years of bilateral support do not seem to have elicited contemporary, locally rooted, competing conceptualisations of disability".

Remaining challenges: lessons from developing countries

A number of challenges remain in developing countries concerning the social and economic inclusion of disabled people. How disability activists, governments, aid

agencies and society at large respond to these will continue to be instructive. As this paper has demonstrated, one major concern is that models aimed at incorporating disability into development policy and practice are often devised in advanced economic contexts and, consequently, are too tightly focused on urban-based populations and environments. For example, the initial work of United Nations Economic and Social Commission for Asia and the Pacific region (UNESCAP) has been to empower urban-based persons with disabilities in mainstream facilities (Parker, 2001). In recognizing the problems with this in developing countries, a long-term strategic intention is to work to raise disability issues in rural areas; this will be a more holistic approach and will include other social and developmental issues such as child labour, exploitation and poverty alleviation. In this sense, then, UNESCAP is responding to the need to include *all* disabled persons in the development process (see also Turmusani (2003) on participatory research with disabled people and Jordan and Parker (2001) on efforts towards participation and inclusion in the more developed Asian economies). A further challenge is ensuring that debates within poorer countries can inform development strategies, but first there needs to be an understanding of what these debates are and an assessment of their potential to inform broader policy and practice. The legislative changes in South Africa and Uganda, and the positive effects these have had in driving the disability rights agenda and energising civil society organisations are instructive in this regard.

Importantly, formal citizenship in South Africa incorporates a notion of cultural citizenship (Stevenson, 2001), in which cultural rights are added to civil, political and social rights. Cultural rights are related to identity and are based on "the right to be different while enjoying full membership of a democratic and participatory community"

(*ibid.* 2); they "herald a new breed of rights claims for unhindered representation, recognition without marginalisation, acceptance and integration without 'normalising' distortion" (*ibid.* 3). For disabled people, this is of significance since against this backdrop, legislation does not simply seek to 'normalise' them as productive contributors in the formal economy (*cf.* Erevelles' case study of South India (2001) and Shang's discussion of employment policies for disabled people in urban China (2000), but to create conditions for acceptance and integration on their terms as disabled people).

Challenges also remain concerning acknowledgement within policy and practice of the interconnections between gender and disability (Lorenzo 2003). Until recently, there has been little consideration by theorists of disability of the ways in which gender might structure the experience of disability (Morris 1994; 1996). Equally:

> It is quite absurd that international development programs rarely address the needs of disabled women. Women with disabilities are harassed sexually, exploited by men, suffer abject poverty and social disrespect, malnutrition, disease and ignorance (Safia Nalule in Mobility International USA 2002).

In spite of critical need, women with disabilities are under-represented and under-served in every aspect of the international development field: as partners, staff and beneficiaries of development schemes. In addition, in much of southern Africa, Latin America and the Caribbean, disability has been the concern of a voiceless minority "cared for" largely by women (Miles 2001); in South Asia women in most settings are more likely than men to experience as well as report poor health and functional impairments but little is known about the association between gender, marital status, co-residence with sons, and disability (Sengupta and Agree, 2002).

Women with disabilities traditionally have not had access to economic development initiatives, even those targeting women. Micro-credit programmes use selection criteria, lending procedures and training facilities that discriminate against women, primarily because of a lack of accessibility, and disabled women often do not have access to vital health information, particularly HIV/AIDS prevention. Coping with disability is a much tougher proposition for women because of unequal access to income-generation opportunities, through male bias in planning and the way that providing care for disabled people is constructed as an exclusively female concern (Snyder 1995). As Power (2001) points out, there are important links between the assumed passivity of disabled people and the assumed passivity of women; the struggle against social stigma is thus more complex for women. The South African legislative and policy context, however, recognises these links and, at least on paper, is progressive; both international development programmes and debates within industrialised countries could learn from this approach.

Similarly, Uganda has adopted a Universal Primary Education policy to provide all children with access to basic education (DfID 2000). The policy provides free education for four children per family, two of which must be girls (where there are girls) and any children with a disability. This represents considerable progress in a context where the education of disabled children might previously have been considered a waste of resources. India also has a District Primary Education Programme in place that seeks to include disabled children in mainstream schools. This is aimed at providing an education for disabled children while challenging the stigma and negative stereotypes often associated with such children (*ibid.*). While significant challenges still remain

concerning policy, infrastructure, issues of empowerment, cultural attitudes, visibility, and the effects of conflict on disability, positive steps are being taken in many developing countries, incorporating the lessons learned from other contexts, but combining these with an understanding of local difference, and having the potential to effect more appropriate policies.

Conclusions

The need to prioritise disability issues in development policy is increasingly recognised. For example, the UK government Department for International Development recently launched a Disability Knowledge and Research Programme and has collated a directory of key information resources entitled "Disability, development and inclusion". This is aimed at organisations working with disabled people in developing countries and covers a wide range of themes including human rights, gender, poverty and mainstreaming, as well as planning and management of disability programmes and service delivery relating to children, community-based rehabilitation, mental health and HIV/AIDS (see www.asksource.info/res_library/disability.htm). However, in planning and practice by development organisations disability remains relatively neglected. South Africa, Uganda and India are examples where relatively poor countries have attempted to tackle head on issues of disability rights and human development, drawing primarily on social models that are now embedded in international frameworks but increasingly recognising the impacts of local factors that limit practical implementation of these. They are also noting the importance of local-level understandings and needs. Each context is, of course, unique and this needs to be acknowledged when attempting to draw lessons from their

548 progression of disability issues. However, they suggest that prioritising the meeting of
549 basic human needs and assuring social justice and equity need to precede addressing
550 issues of access for disabled people. This is particularly relevant, as Komardjaja (2001b,
551 101) argues, in cultures of coping, tolerance and survival where marginalization is less of
552 an issue than it might be in industrialised countries.

553 What sets disability issues in developing countries apart is that it is difficult to
554 encounter them without conceptualising disability as a product of both the traumatic
555 processes of colonialism and the often problematic construction of postcolonial national
556 identities. This is particularly the case in Africa, where, as Quayson (2002, 228) argues:

557 > [W]ars and rumours of war succeed in proliferating disability on the streets
558 > daily. Angola, Mozambique, Liberia, Rwanda, Sierra Leone. In all these countries
559 > reckless wars have ensured that the disabled are part of everyday life. In any
560 > attempt to create a civil imagining in these countries, the problem will always be
561 > how to confront a traumatic history of disability at the personal as well as the
562 > social level.

563 There is thus a need for a more holistic and flexible approach to understanding disability,
564 with a greater focus on local and individual experience and on recognising the importance
565 of geopolitical, social and cultural as well as economic contexts. This is one welcome
566 lesson from social models of disability. However, individual experience is constituted by
567 biology (being a body of flesh and blood), social discourse (including ideas about
568 'normal' bodies), interactions with social constructs, other people and institutions (Butler
569 and Bowlby 1997). The fact that these factors differ spatially suggest that models of
570 disability also need to be flexible.

Finally, what is striking about much international debate is a failure to recognise 'development' itself as potentially disabling. As Power (2001) argues, to do so is to begin to open up quite profound questions about the margins of 'development' and its impulse to objectify the marginal. Indeed, "To add disability to a development agenda as if it was some kind of cumulative list of needs means that the underlying ableist assumptions of development remain unchallenged" (*ibid.* 95). Related to this is a need to theorise development and disability in both local and global contexts, for both a deeper understanding of disability issues by those involved in the development field and of developing world issues by those involved in the disability field (Stone 1999). There is also a need for greater networking between those involved in disability and development in poorer countries (Hurst 1999), which would greatly enhance the possibilities of theorising from these contexts and producing more locally appropriate policies and practice.

References:

Ballard R and Popke J 2004 Dislocating modernity: identity, space and representation of street trade in Durban, South Africa *Geoforum* 35 1 99-110

Barnes C 1991 *Disabled people in Britain and discrimination: a case for anti-discrimination legislation* Hurst and Co, London

Bartlett S 2002 The problem of children's injuries in low income countries: a review *Health Policy and Planning* 17 1 1-13

Baylies C 2002 Disability and the notion of human development: questions of rights and capabilities *Disability and Society* 17 7 725-39

Berger LR and Mohan D 1996 *Injury control: a global view* New Delhi Oxford University Press

Bickenbach J, Chatterji S, Badley E and Ustun T 1999 Models of disablement, universalism and the international classification of impairments, disabilities and handicaps *Social Science and Medicine* 48 1173–1187

Butchart A, Kruger J, Lekoba R and Smith D 1996 Evaluating injury prevention outcome in a developing country context: lessons from a community-based violence prevention programme *Urbanisation and Health Newsletter* 29th June 28-42

Butler R and Bowlby S 1997 Bodies and spaces: an exploration of disabled people's use of public space *Environment and Planning D: Society and Space* 15 4 411-33

Bond P 2000 *Elite Transition: From Apartheid to Neo-Liberalism in South Africa* Pluto, London

Cape Business News Disabled people ask for equality 26/11/01 http://www.cbn.co.za/issue/11120103.htm

CASE 2002 'We also Count'. The extent of moderate to severe reported disabilities and the nature of the disability experience in South Africa http://www.case.org.za/htm/wecount2.htm

Chambers R 1983 *Rural development: putting the last first* Harlow Longman

Deen JL, Vos T and Huttley SR 1999 Injuries and communicative diseases: emerging health problems of children in developing countries *Bulletin of the World Health Organisation* 77 518-24

Devlieger PJ 1998 Physical disability in Bantu languages: understanding the relativity of classification and meaning *International Journal of Rehabilitation Research* 21 51-62

DfID 2000 *Disability, Poverty and Development*

Dewsbury G, Clarke K, Randall D, Rouncefield M and Sommerville I 2004 The anti-social model of disability *Disability and Society* 19 2 145-158

Erevelles N 2001 Disability and the political economy of place: case study of a voluntary organisation in South India *Disability Studies Forum* 21 4 5-19

Flower J and Wirz S 2000 Rhetoric or reality? The participation of disabled people in NGO planning *Health Policy and Planning* 15 2 177-185

Forjuoh SN and Gyebi-Ofusu E 1993 Injury surveillance: should it be a concern for developing countries? *Journal of Public Health Policy* 14 355-9

Gatjens LF 2004 Disability and human rights in Latin America *Disability World* 24 http://www.disabilityworld.org/06-08_04/news/humanrights.shtml

Gleeson B 1999 *Geographies of disability* Routledge, London and New York

Goffman E 1963 *Stigma: Notes on the Management of Spoiled Identity* Prentice-Hall, New Jersey

Guastello SI 1999 Injury analysis and prevention in developing countries *Accident and Analysis and Prevention* 31 295-6

Hart G 2002 *Disabling globalization: places of power in post-apartheid South Africa* University of Natal Press, Pietermaritzburg

Harriss-Whyte B 1997 The political economy of disability and development with special reference to India *UNRISD DP* 73

Helander E 1992 *Prejudice and dignity: an introduction to community based rehabilitation* UNDP

639 **Hughes B and Paterson K** 1997 The social model of disability and the disappearing
640 body: towards a sociology of impairment *Disability & Society* 12 3 325-340
641 **Hurst R** 1999 Disabled People's Organisations and Development: strategies for Change
642 in **Stone E** ed *Disability and development* Leeds Disability Press, Leeds 25-35
643 **ILO** 1989 *Introduction to social security* (3rd Edition) International Labour Office
644 **Imrie R** 2004 Demystifying disability: a review of the *International Classification of*
645 *Functioning, Disability and Health Sociology of Health and Illness* 26 3 287-305
646 **Ingstad B** 1999 The myth of disability in developing nations *Lancet* 354 756-7
647 **Kabzems V and Chimedza R** 2002 Development assistance: disability and education in
648 Southern Africa *Disability and Society* 17 2 147-57
649 **Kisanji J** 1995 Growing up disabled in **Zinkin P and McConachie H** eds *Disabled*
650 *children and developing countries* MacKeith Press, London 183-202
651 **Komardjaja I** 2001a New cultural geographies of disability: Asian values and the
652 accessibility ideal *Social and Cultural Geography* 2 1 77-86
653 **Komardjaja I** 2001b The malfunction of barrier-free spaces in Indonesia *Disability*
654 *Studies Quarterly* 21 4 97-104
655 **Krug EG Sharma GK and Lozano R** 2000 The global burden of injuries *American*
656 *Journal of Public Health* 90 523-6
657 **Laflamme L and Diderichsen F** 2000 Social differences in traffic injury risks in
658 children and youth – a literature review and research agenda *Injury Prevention* 6 293-8
659 **Lee S** 1997 WHO and the developing world: the contest for ideology in **Cunningham A**
660 **and Andrews B** eds *Western medicine as contested knowledge* Manchester University
661 Press, Manchester and New York 24-45

662 **Lorenzo T** 2003 No African renaissance without disabled women: a communal approach
663 to human development in Cape Town South Africa *Disability and Society* 18 6 759-778
664 **Marais H** 1998 *South Africa: limits to change. The political economy of transition* Zed
665 Books, London
666 **Marks D** 1999 *Disability: controversial debates and psychosocial perspectives*
667 Routledge, London.
668 **Metts RL and Metts N** 2000 Official development assistance to disabled people in
669 Ghana *Disability and Society* 15 3 475-488
670 **Meyer AA** 1998 Death and disability from injury: a global challenge *Journal of Trauma*
671 44 1-12
672 **Miles M** 1996 Community, individual or information development? Dilemmas of
673 concept and culture in south Asian disability planning *Disability and Society* 11 4 485-
674 500
675 **Miles M** 1992 Concepts of mental retardation in Pakistan: toward cross-cultural and
676 historical perspectives *Disability, Handicap and Society* 7 3 235-55
677 **Miles M** 2001 History of educational and social responses to disability in Anglophone
678 eastern and southern Africa: introduction and bibliography *The History of Education and*
679 *Childhood* http://www.socsci.kun.nl/ped/whp/histeduc/mmiles/aesabib.html (updated
680 20/12/01)
681 **Millward H, Ojwang VP, Carter JA and Hartley S** 2005 International guidelines and
682 the inclusion of disabled people. The Ugandan story *Disability and Society* 20 2 53-167

683 **Mobility International USA** 2002 Building support for disabled women within
684 development programs *Disability World* 13 http://www.disabilityworld.org/04-
685 05_02/women/support.shtml
686 **Morris J** 1994 Gender and disability. In Swain J, Finkelstein V, French S and Oliver M
687 eds. *Disabling barriers - enabling environments* Sage, London 85-92
688 **Morris J** 1996 (ed) *Encounters with strangers: feminism and disability* The
689 Women's Press, London
690 **Oliver M** 1990 *The politics of disablement* Macmillan, London
691 **Parker K** 2001 Changing attitudes towards persons with disabilities in Asia *Disability*
692 *Studies Quarterly* 21 4 105-113
693 **Power M** 2001 Geographies of disability and development in Southern Africa *Disability*
694 *Studies Quarterly* 21 4 84-97
695 **Priestley M** 1995 Commonality and difference in the movement: an "Association of
696 Blind Asians" in Leeds *Disability and Society* 10 2 157-169
697 **Quayson A** 2002 Looking awry: tropes of disability in postcolonial writing in **Goldberg**
698 **DT and Quayson A** eds *Relocating postcolonialism* Blackwell, Oxford 217-30
699 **Rao S** 2001 'A little inconvenience': perspective of Bengali families of children with
700 disabilities on labelling and inclusion *Disability and Society* 16 4 531-48
701 **Rowland W** South Africa D/@bility *Disability World* 13
702 http://www.disabilityworld.org/04-05_02/employment/southafrica.shtml
703 **Sengupta M and Agree EM** 2002 Gender and disability among older adults in north and
704 south India: differences associated with co-residence and marriage *Journal of Cross-*
705 *cultural Gerontology* 17 4 313-336

706 **Shang X** 2000 Bridging the gap between planned and market economies: employment
707 policies for disabled people in two Chinese cities *Disability and Society* 15 1 135-156
708 **Sharma AK, Sarin YK and Manocha S** 1993 patterns of childhood trauma: Indian
709 perspectives *Indian Paediatrics* 30 57-60
710 **Snyder M** 1995 *Transforming development: women, poverty and politics* Intermediate
711 Technology Publications, London
712 **Stevenson N** ed 2001 *Culture and citizenship* Sage, London
713 **Stone E** 1997 From the research notes of a foreign devil: disability research in China in
714 **Barnes C and Mercer G** eds *Doing disability research* Leeds Disability Press, Leeds
715 **Stone E** 1999 Disability and Development in the Majority World in **Stone E** ed
716 *Disability and development* Leeds Disability Press, Leeds 1-18
717 **Tregaskis C** 2002 Social model theory: the story so far… *Disability and Society* 17 4
718 457-70
719 **Turmusani M** 2003 *Disabled people and economic needs in the developing world: a*
720 *political perspective from Jordan* Ashgate, Aldershot
721 **Truter L** 2001 Disability: the quest for reform *Law, Democracy and Development* 4 75-
722 85
723 **Whyte SR and Ingstad B** 1995 Disability and culture: an overview in **Whyte SR and**
724 **Ingstad B** eds *Disability and culture* University of California Press, Berkeley 1-22
725 White Paper for Social Welfare GN 1108 in *Government Gazette* 18166 of 1997
726 White Paper on an Integrated National Disability Strategy (1997)
727 www.polity.org.za/govdocs/white_papers/disability1.html

728 **World Health Organisation** 2001 *International Classification of Functioning, Disability*
729 *and Health (ICF)* WHO, Geneva
730 **Zwi AB, Forjuoh S, Murugusampillay S, Odero W and Watts C** 1996 Injuries in
731 developing countries: policy responses needed now *Transactions of the Royal Society of*
732 *Tropical Medicine and Hygiene* 90 593-5